

**White House Conference on Aging  
Designated Aging Agenda Event  
Summary Report**

**Giving Voice to Quality:  
A Consumer Dialogue on Facility-Based Long-Term Care**

**Washington, DC  
April 29, 2005**

Sponsoring Organizations:

**National Citizens' Coalition for Nursing Home Reform  
National Academy of Elder Law Attorneys  
National Association of State Long-Term Care Ombudsman Programs  
National Association of Local Long-Term Care Ombudsmen  
Center for Medicare Advocacy**

Number of persons attending: 90

Host: National Citizens' Coalition for Nursing Home Reform

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For more information about this event including presentations on each resolution, please visit [www.nursinghomeaction.org](http://www.nursinghomeaction.org)

## **Giving Voice to Quality: A Consumer Dialogue on Facility-Based Long-Term Care**

Over 90 people – residents, family members, ombudsmen, direct care workers, elder law attorneys, citizen advocates, and policy makers – came together in a public forum held in Washington DC on April 29, 2005. They represented many racial, ethnic, cultural and language groups. There were young adults, baby boomers and older persons united in a single voice, with passion and determination to make change, articulating the need for quality care and quality of life for those who may need and/or prefer a facility-based setting to receive long-term care services now and in the future

Elma Holder, founder of the National Citizens' Coalition for Nursing Home Reform, set the stage in her keynote address, "Long-term Care Living: The Nation's Challenge" with a reminder to celebrate an outstanding public law, the Nursing Home Reform Law of 1987 (NHRL), but not to rest until it is fully implemented.

*If the tenets of our national nursing home reform law are learned, understood, appreciated and practiced, a nursing facility can and will offer a high quality, supportive and nurturing culture for its residents and also its staff.... We are proud of this law for it speaks to and for everyone living in a nursing facility and for those of us in this room who are, according to statistics, potential residents.... We have a clear direction and a strong foundation for good care in nursing homes. But, alas, it is not that simple – and surely each of us in this room knows that fact. – Elma Holder*

Following the presentation of draft resolutions and impassioned responses by a variety of speakers, the forum produced four resolutions (see Appendix) that reflect consensus by the sponsoring organizations and the participants of this historic event.

The issues in the resolutions are presented below in priority order, listing barriers and proposed solutions for each.

### **Priority Issue # 1: Comprehensive national policy for facility-based long-term care that addresses quality of care and quality of life for older people and people with disabilities** (Related to WHCOA agenda item "Health and Long-Term Living").

Current and future residents need and deserve care that is based on the principles of the NHRL – individualized care, respect for resident rights, and services that enable them to continue living independently. Such a comprehensive national policy should also assure culturally competent care; address nurse staffing issues, including adequate numbers as determined by evidence-based research, training, and retention; and provide adequate public support for those who need financial assistance.

#### **Barriers:**

- No required minimum staffing standards
- Inadequate and poor quality care
- Short staffing due to low wages and competition with other industries
- High staff turnover

- No national standards of care in assisted living, board and care and other long-term care facilities that are not covered by the Nursing Home Reform Law

### **Proposed Solutions:**

- Full implementation and enforcement of the NHRL
- Reinforcement of the survey process that determines compliance with standards, including adequate numbers of inspectors and unannounced visits
- Enactment of legislation that applies the principles of the NHRL regarding high quality of care, high quality of life, residents rights, and recognition of individual needs throughout the realm of facility-based care, including assisted living and board and care residences
- Establishment of staffing requirements supported by evidence-based research
- Enactment of policies to reduce direct care staff turnover, increase opportunities for staff development, and create a supportive work environment; policies to ensure adequate living wage compensation including health care; procedures to collect, audit, and report direct care staffing in a manner accessible and understandable to the public; and
- Enactment of a comprehensive publicly-supported system to pay for long-term care services in facility-based settings

*There are times that we are not able to make the simplest changes to our routine, because it is not convenient. I am lucky because I can speak for myself, but many of my friends in the nursing home can't or won't because they are afraid they will just be ignored. We do not want to be forgotten in the middle of a huge number of tasks. We are people who just happen to live in nursing homes. – Nursing Home Resident*

### **Priority Issue # 2: Individualized care and services; resident-directed care, including independent resident and family councils; and deep culture change in long-term care settings** (Related to WHCOA agenda item “Health and Long-Term Living: Delivery of Quality of Care by Caregivers”).

The principles of individualized care and services as defined in the 1987 Nursing Home Reform Law should apply to all residents of all long-term care facilities, including board and care and assisted living. These facilities should be viewed as homes where deep culture change nurtures the human spirit while meeting medical needs, follows the resident's routine rather than those imposed by the facility, and encourages a person-centered, interdisciplinary, staff team focus that respects the right of residents to be treated as individuals who have the right to make their own decisions.

### **Barriers:**

- Scheduling of care planning conferences tends to be inflexible and without regard for the needs of residents and family members
- Residents and families, as well as direct care staff, are not adequately included in the care planning process
- Residents and family members are hesitant to express their concerns for fear of retaliation against them
- Facility schedules and services such as meal times, therapy, recreation, bathing and other essentials of quality living often do not take into consideration diversity and individual needs of residents.

**Proposed Solutions:**

- Congress and other federal and state departments and agencies shall enact and implement appropriate laws, regulations, initiatives and policies that foster and provide incentives for incorporating the philosophy and vision of deep culture change as an important component of quality of care and quality of life for individuals in all long-term care settings
- Centers for Medicare & Medicaid Services (CMS) and state regulatory agencies shall promulgate and enforce regulations that provide residents the opportunity to make and execute meaningful decisions in all aspects of their lives
- CMS and states shall promulgate and enforce regulations to strengthen the ability of independent family councils and resident councils to improve the quality of care and quality of life in nursing homes and promote family involvement without fear of retaliation.

*We often feel frustrated as family members that we are part of a system that sometimes is not responsive to the needs of residents who cannot express themselves.... The culture needs to change ...to a culture of life, health, and well-being of the resident. This is not too much to demand of our healthcare system, which most of us will depend on in the future. – Family Council Member*

**Priority Issue # 3: The Long-Term Care Ombudsman Program** (Related to WHCOA agenda item “Health and Long-Term Living”).

Conceived by Dr. Arthur Flemming, established and defined by the 1978 amendments to the federal Older Americans Act, and no less important today, the primary role of the Long-term Care Ombudsman Program is to promote and protect the rights of residents before, during and after their placement in long-term care facilities. Residents must have immediate and uninterrupted access to ombudsmen who can advocate for their rights and assist them in making informed decisions and choices in their care and treatment.

**Barriers:**

- Lack of adequate funding, resulting in residents not having consistent access to ombudsman
- Need for programs unhindered by state or local government efforts or employers attempting to influence or interfere with individual or system advocacy
- Need for additional training and immediate access to information on a variety of complex issues

**Proposed Solutions:**

- Congressional support for funding that will meet or exceed the 1:2000 ombudsman-to-resident ratio as identified in the Institute of Medicine study for the Long-term Care Ombudsman Program
- Congress and the federal government’s reaffirmation and enforcement of the Long-term Care Ombudsman Program’s independence as described in §712(a)(4)(B)(i) of the Older Americans Act
- Permanent and adequate funding for the National Ombudsman Resource Center

*An ombudsman is both an advocate and a quality controller. Not assuring quality of items packaged into a box, but of human beings sharing a home because they need care. – Local Ombudsman*

**Priority Issue # 4: Federal government role in guaranteeing access to health care services for the most vulnerable of our population, such as the elderly, low-income, and disabled citizens** (Related to WHCOA agenda item “Health and Long-Term Living: Adequate access to state and federal health care programs including Medicare and Medicaid”).

The health care needs today are to some extent different from the health care needs of 35 years ago. People are living longer with chronic conditions. We need a publicly-financed way to pay for the chronic health care needs of older people and people with disabilities.

**Barriers:**

- No comprehensive system for providing long-term care is in place
- Medicaid is the *only* safety net for long term care consumers
- Low and middle-income Americans have no other option for meeting the catastrophic costs of long-term care other than Medicaid
- Medicaid is the only public financing program covering long-term care services for seniors and others who have physical and cognitive limitations that impair their ability to live independently.

**Proposed Solutions:**

- Maintain comprehensive federal standards of eligibility, coverage, and administration for Medicaid with state flexibility to expand eligibility and coverage
- Ensure that federal Medicaid funding to states is not subject to a cap or a “block grant”
- Enforce nursing home regulations and standards of care as outlined in the 1987 Nursing Home Reform Law
- Ensure that all long-term care services financed in whole or in part by Medicaid comply with federal standards

*One simply cannot talk about facility based long term care without talking about Medicaid. It sets forth in rich detail the quality of care residents are entitled to receive and the quality of life they are supposed to experience and enjoy. It addresses virtually every aspect of nursing home life and it protects all nursing home residents in Medicaid certified facilities, regardless of whether or not they receive Medicaid themselves. – Citizen Advocate*

**Conclusion**

The participants in this dialogue -- young, old, African-American, Caucasian, Hispanic, Asian, able-bodied, mobility impaired, families, workers, and persons in the community including residents of facilities -- asked not for extraordinary measures. They asked for full implementation and enforcement of the NHRL. They asked for living conditions and working conditions that meet basic human needs and rights. They asked to be treated with dignity and respect in all settings, now and in the future. They asked to be remembered and heard at the 2005 White House Conference on Aging.

# APPENDIX

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[Resolution 1](#): Comprehensive National Policy for Facility-Based Long-Term Care

[Resolution 2](#): Ensuring Quality of Life in Long-Term Care Facilities

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[Resolution 4](#): Medicaid and Long-Term Care

## **RESOLUTION ON A COMPREHENSIVE NATIONAL POLICY FOR FACILITY-BASED LONG-TERM CARE**

*WHEREAS* older people and people with disabilities who have acute and chronic illnesses may be unable to continue living independently, despite their preference to do so; and

*WHEREAS* older people and people with disabilities may need and/or prefer a facility-based setting to receive long-term care services; and

*WHEREAS* older people and people with disabilities maintain all their Constitutional rights and their interests in autonomy and in maintaining maximum control over their lives to the greatest extent possible, regardless of where they live; and

*WHEREAS* older people and people with disabilities need and deserve high quality care and services in facility-based settings, regardless of the facility's type and classification under state and federal law; and

*WHEREAS* older people and people with disabilities may need assistance with paying for facility-based care but are sometimes denied assistance because Medicare pays for limited long-term care services that are tied to an acute care episode and Medicaid pays only for people who are poor;

**NOW, THEREFORE, BE IT RESOLVED** that the 2005 White House Conference on Aging support:

Full implementation and enforcement of the federal Nursing Home Reform Law of 1987 to assure that residents of nursing facilities receive high quality of care, high quality of life, full respect for their rights, and recognition of their individual physical, psychological, social and spiritual needs and preferences; and

Enactment of legislation to assure that residents of other facility-based long-term care settings, such as assisted living and board and care residences, receive high quality of care, high quality of life, full respect for their rights, and recognition of their individual needs, including cultural, ethnic and linguistic preferences; and

Establishment and enforcement of:

- fact-based minimum staffing requirements for all facility-based care settings sufficient to meet residents' needs;
- initial and on-going training requirements for all direct care staff to ensure they have adequate knowledge to provide high quality care;
- policies to reduce direct care staff turnover, increase opportunities for staff development, and create a supportive work environment;
- policies to ensure adequate living wage compensation including health care coverage for direct care staff in recognition of the importance of the work they do;
- procedures to collect, audit, and report direct care staffing data by racial, ethnic and language groups and in a manner accessible and understandable to the public; and

Enactment of a comprehensive publicly-supported system that is not tied to acute care needs or poverty to pay for long-term care services in facility-based settings.



## **RESOLUTION ON ENSURING QUALITY OF LIFE IN LONG-TERM CARE FACILITIES**

*WHEREAS* the passage of the 1987 Nursing Home Reform Law brought important standards and regulations to ensure each individual nursing facility resident the right to “care and services to attain or maintain the highest practicable physical, mental and psychosocial well being;” and

*WHEREAS* the 1987 Nursing Home Reform Law recognized the need to create new ways of living and working together different from a traditional medical model; and

*WHEREAS* the principles of individualized care and services as defined in the 1987 Nursing Home Reform Law should apply to all residents of all long-term care facilities including board and care and assisted living; and

*WHEREAS* across the nation singular efforts have been undertaken during recent years to promote deep culture change in different ways that nurture the human spirit as well as meeting medical needs, follow the resident’s routine rather than those imposed by the facility, and encourage a person-centered, multi-involved, staff team focus that respects the right of residents to be treated as individuals who have the right to make their own decisions; and

*WHEREAS* persons who live in long-term care facilities should direct their own care including full participation in the care planning process and in independent resident council meetings where they are able to meet and discuss concerns without fear of reprisal; and

*WHEREAS* many families, personal representatives, and friends of residents are in long-term care facilities many hours each day and are a vital component in improving quality of care and quality of life for residents, but are hesitant to express their concerns over care for fear of retaliation in many forms against them or their resident loved one;

**NOW, THEREFORE, BE IT RESOLVED THAT** Congress, the Centers for Medicare & Medicaid Services, Administration on Aging, and other federal and state departments and agencies foster and provide incentives for incorporating the philosophy and vision of deep culture change as an important component of quality of care and quality of life for individuals in all long-term care settings, with appropriate laws, regulations, initiatives and policies; and

**BE IT FURTHER RESOLVED THAT** the Centers for Medicare & Medicaid Services and state regulatory agencies promulgate and enforce regulations that provide residents the opportunity to make and execute meaningful decisions in all aspects of their lives and provide for timely, comprehensive responses from facility staff to issues raised by individual residents and independent resident councils; and

**BE IT FURTHER RESOLVED THAT,** the Centers for Medicare & Medicaid Services and state regulatory agencies promulgate and enforce regulations to strengthen the ability of independent family councils to improve the quality of care and quality of life in nursing homes and promote family involvement without fear of retaliation.

Notes: Culture Change includes the Eden Alternative, Regenerative Community, Resident Directed Care, Individualized Care, and the Pioneer Movement that promote resident centered care rather than a traditional medical model. See the Visions and Mission of Culture Change at [www.pioneernetwork.net](http://www.pioneernetwork.net)



## **RESOLUTION ON THE LONG-TERM CARE OMBUDSMAN PROGRAM**

*WHEREAS* the 1978 amendments to the federal Older Americans Act established and defined the important role of the Long-term Care Ombudsman Program to promote and protect the rights of residents before, during and after their placement in long-term care facilities; and

*WHEREAS* the cornerstone of the Long-term Care Ombudsman Program has always been for residents to have immediate and uninterrupted access to ombudsmen who can advocate for their rights and assist residents in making informed decisions and choices in their care and treatment - without undue influence or impediment; and

*WHEREAS* the Older Americans Act mandates, and independent research confirms, that the work of the Long-term Care Ombudsman Program is best accomplished in an environment where there are no efforts by state or local government or employers to influence or interfere with individual or system advocacy activities of the program that are resident directed (IOM report; Bader Report; ABA Ombudsman Standards); and

*WHEREAS* in order for the Long-term Care Ombudsman Program to perform at maximum effectiveness and fully achieve complaint resolution for consumers of long-term care services, it requires adequate funding, program neutrality, and immediate access to a central source of current, reliable information and training;

**NOW, THEREFORE, BE IT RESOLVED** that the White House Conference on Aging support:

Congressional support for funding that will meet or exceed the 1:2000 ombudsman-to-resident ratio as identified in the Institute of Medicine study for the Long-term Care Ombudsman Program through the Administration on Aging (AoA) and from the Centers for Medicare & Medicaid Services (CMS) through the Medicare Trust Fund; and

That Congress and the federal government reaffirm and enforce the Long-term Care Ombudsman Program's independence as described in §712(a)(4)(B)(i) of the Older Americans Act in order to operate in an environment free from conflict with the full capacity to represent resident interest to public officials and to be effective advocates for residents; and

That Congress direct the Administration on Aging to ensure permanent and adequate funding for the National Ombudsman Resource Center to equip, through training and information, Long-term Care Ombudsmen in their advocacy for persons in long-term care facilities.

## **RESOLUTION on MEDICAID AND LONG-TERM CARE**

*WHEREAS* all Americans deserve access to a comprehensive package of high-quality health care, including long-term care; and

*WHEREAS* until a comprehensive system for providing long-term care is in place, the federal government has a role in guaranteeing access to health care services for the most vulnerable of our population, such as the elderly, low-income, and disabled citizens; and

*WHEREAS* Medicaid is the only public financing program covering long-term care services for seniors and others who have physical and cognitive limitations that impair their ability to live independently; and

*WHEREAS* low and middle-income Americans have no other option for meeting the catastrophic costs of long-term care other than Medicaid; and

*WHEREAS* Medicaid provides quality standards and an inspection and enforcement system that protects *all* nursing home residents – whether or not they receive Medicaid;

**THEREFORE, BE IT RESOLVED** that the 2005 White House Conference on Aging support policies that:

Maintain comprehensive federal standards of eligibility, coverage, and administration for Medicaid with state flexibility to expand eligibility and coverage and strengthen administrative practices; and

Ensure that federal Medicaid funding to states is not subject to a cap or a “block grant;” and

Ensure that Medicaid beneficiaries have the ability to choose and participate in any and all decisions regarding the nature, timing, and setting for delivery of their care; and

Ensure that nursing home regulations and standards of care as outlined in the 1987 Nursing Home Reform Law are enforced and that all long-term care services financed in whole or in part by Medicaid comply with federal standards; and

Ensure that Medicaid Section 1115 waivers improve the quality, delivery, and effectiveness of care through demonstrations and innovations and that they are not used to reduce access to appropriate services for anyone who needs them, nor diminish the quality of care, nor make the federal income, asset, or spousal impoverishment rules more restrictive.